# **Children's Disability Services Workgroup Minutes**

Meeting #3 September 13, 2011, 10:00 am to 3:15 pm West Des Moines Library, Community Room 4000 Mills Civic Parkway, West Des Moines, IA 50265

## **MINUTES**

#### **Attendance**

**Workgroup Members:** Wendy Rickman/Chair, Marilyn Althoff, Gail Barber, Nicole Beaman, Paula Connelly, Julie Curry, Jim Ernst, Jerry Foxhoven, Jason Haglund, Jan Heikes, Janice Lane, Marilyn Lantz, Samantha Murphy, Rhonda Shouse, Jason Smith, David Stout, Debra Waldron

**Legislative Representation:** Jack Hatch, State Senator, District 33 (Polk County) and Co-chair of the Legislative Interim Committee on MHDS Redesign

**Facilitator:** Kevin Martone, Technical Assistance Collaborative

**DHS Staff:** Joanna Schroeder, Laura Larkin, Carmen Davenport,

Theresa Armstrong

Other Attendees:

Liz O'Hara CDD Melissa Fitzgerald Sequel

Beth Jones Iowa Department of Public Health (IDPH)

Deb Dixon IDPH Gretchen Hagman IDPH

Dan Royer Iowa Hospital Association
Deborah Thompson Legislative Services Agency
Sandi Hurtado-Peters Iowa Dept. of Management

Vickie Miehe Child Health Specialty Clinics/Community Circle of Care

Martha Munro

Sara Eide Mercy Health Network

Linda Hinton Iowa State Association of Counties

Josh Bronsink Senate Republicans

David Basler Child Serve

Lori Elam Scott County CPC

David Adelman Iowa Academy of Pediatrics

Joan Discher Magellan

Nicole Rand Exceptional Persons, Inc.
John Pollack Legislative Services Agency
Anne Discher Child & Family Policy Center

Kris Bell SDC

Kristi Oliver Coalition for Family & Children Services
Deanna Triplett Iowa Behavioral Health Association

Brad Trow House Republican Staff

Bob Thacker Northeast Iowa Behavioral Health

## **Agenda**

Agenda Topics:

- Outlining a framework for bringing kids home (continuation from previous session).
- Core treatment services for children and families that will ensure successful return to least restrictive home/community setting.

### **WORKGROUP OVERVIEW**

Wendy Rickman welcomed the workgroup and audience to the Children's Workgroup meeting and introduced Julie Curry who has been a member of the workgroup but was the first week she was able to attend. Ms. Curry introduced herself and highlighted her personal and professional experience working with youth. She is passionate about seeing the changes made with this workgroup.

Joel Fry also joined the group for the first time. He is the Representative from House District 95 and is the Legislative Representative for the Children's Disability Services Workgroup. Mr. Fry introduced himself and shared that he is very excited that this process has begun again. He stressed how both the Democrats and Republicans want this problem addressed. He reported that we need to practice due diligence to get our clients the services they need in Iowa. He shared that he has experience in mental health practice and pediatrics.

Senator Hatch joined the workgroup and Ms. Rickman briefed him on what the workgroup had done to date with an emphasis on developing a system of care to serve youth and families, thinking outside the box to craft what a youth and the family needs, and attacking the charge to bring the out of state (OOS) youth back to lowa while preventing other youth from going OOS for services/placement. The workgroup needs to identify the gaps in services now and develop a plan to implement over the next couple of years.

Kevin Martone facilitated the workgroup in lieu of Kappy Madenwald who was unable to attend. He began by highlighting three topics from previous meetings:

- The group needs to focus on developing a system of care over an extended period of time as compared with the other workgroups, including but not limited to returning children placed out of state, identifying gaps in services, and establishing planning provisions to be carried out over the next year.
- This work will go to the Legislature for action and will be considered also by the Regional Workgroup who is tasked with creating regional areas in the state of lowa.
- Here is where the workgroup is to date:
  - o lowa is evolving towards a commitment to services for youth and families.
  - Focus on working with the toughest youth and their families who have the most needs in the system.
  - Important to serve youth in lowa vs. sending them out of state for services/placement.
  - Develop a system of care for youth and families with specific outcomes, ways to measure accountability and in the most integrated and least restrictive setting.

Martone began the discussion by focusing on what will be needed within the framework of a system of care and asking the workgroup to recap highlights from the last meeting. The workgroup emphasized the need to not only develop a system of care to bring youth back to lowa, but to identify the funding streams for the services the youth will need to maintain/sustain the youth in lowa. While some youth have the benefit of private insurance along with lowa Medicaid, private insurance does not pay for all the services a youth may need. Martone also emphasized the need to begin looking at prevention and diversion opportunities in terms of how to keep youth in lowa.

While the group has a longer period to conduct its work, the legislature is expecting some concrete recommendations that may be implemented now, especially related to out of state placements. There may be windows of opportunity that would add value to the service system now that could lay a foundation for the youth system and to stage this as a return on lowa's investment when bringing youth back to lowa.

The workgroup will need to identify the following as they move to a system of care:

- Identify core services that are needed to develop a system of care.
- · Identify the gaps in service and the intercepts that are present.
- Identify what lowa could have done to keep youth from going out of state.
- Legislature has asked for a gaps analysis for the out of state youth and what
  planning process could be developed to bring them back to lowa and prevent
  youth from leaving lowa for necessary services.
- Identify current services and what lowa could do to improve the system.
- Identify the needs of all children ages 0-18.

Director Palmer reminded the workgroup they need to develop concrete recommendations for the Legislature. The concrete recommendations need to address the basic functions of a system of care and what the expected outcomes will be for the

youth and families and build core services and how they will interface with a system of care. He also asked the workgroup to move forward expeditiously despite having a longer timeframe to complete the work. The Legislature is very interested in what this workgroup is doing.

A number of workgroup members offered information from their professional experiences in the workplace. The following were comments provided by workgroup members:

- There are many kneejerk reactions; youth are often brought to the hospital ER
  with in hopes that an inpatient psychiatric stay will result in better access to
  services. Many are referred inappropriately from the schools. The hospital is
  working with the local school district and what the ER visit may/may not produce
  for the youth and family.
- Many families have noted that services need to be culturally competent and to take into consideration that many families do want their youth to remain at home versus in an out of home placement.
- Services are not available to youth with dual diagnoses. There are also gaps for youth with mental health and intellectual disability diagnoses. It is important to build services based on specific abilities and needs, and to move away from "billing code" issues and to focus on deliverables.
- There needs to be flexibility in services so it works for all very young children
  regardless of where they live rural or urban. This is where thinking outside the
  box will be crucial.
- There are two groups of youth: youth who are too difficult to manage behaviorally and youth who have parents/guardians who are not able to advocate for them.
- This is an opportunity to get a framework that does not limit our capacities to solve bigger system issues. There is not a need for more PMIC beds, but a need to use the current PMIC beds effectively and efficiently. This is our opportunity to build a strong community based services for youth and families.
- lowa's capacity limits lowa providers from serving youth and families. lowa needs
  more beds in ICF-MRs and child welfare. HCBS waivers also need to have more
  options to serve youth in their homes. There is a huge gap in services for low
  functioning violent youth.
- System changes take 5-10 years. Iowa has youth developing now that needs to be supported by the system and their families so they can grow. We have an opportunity to influence the legislature and to strengthen systems now.
- The charge is two-pronged: bring youth back to lowa and to prevent youth from leaving lowa. Youth need to be a part of their family.
- lowa needs to free up monies to bring youth back to lowa so they can be part of their family.
- Schools need to be a team player where youth are concerned. School personnel
  often lack the expertise to deal with disruptive behaviors and need to be willing to
  commit to educate/serve challenging youth.

There was a lengthy discussion related to the core treatment services for youth and their families. The System of Care highlights the youth and family being at the center of the circle, and core services and the infrastructure in the outer circles.

References were made to the definition of the System of Care on a handout from the 08/30/11 workgroup meeting.

The following ideas were presented by the workgroup members for inclusion in the definition of System of Care:

- Funding needs to be flexible to serve the youth and their family. No 'wrong door' for the youth and their family.
- Structure services around the youth and family so they can maintain living in the community.
- Need a continuum of service, not episodes/events of services. For example, crisis.
- Need for freedom and flexibility with service providers.
- Flexibility for the family to use the funding.
- Flexibility with the diagnoses.
- Focus on the Olmstead Plan. Outcomes are encompassed in the definition.
- Healthcare Reform will begin in 2014. We need to talk about the essential benefits package and identify what we would like to see in the essential benefits package.
- lowa Medicaid is looking at how this project will fit into the Affordable Healthcare Act

The System of Care in Northeast Iowa uses a team approach with community providers coming in and out of the team as needed. The communities in Northeast Iowa buy into the program. Ms. Rickman shared that Iowa 'grows things locally' versus on a broadbased basis across the state. The philosophy and framework for a system of care is based on the premise that local flavor is needed to make it work and counties and communities must come together to make it happen for the youth and family. The role of the family navigator, which is now a Magellan funded service, is crucial to the system of care. Family navigators are being used, but we need to look at sustainability in the future when funding may be in jeopardy.

Outcomes for the system of care need to be standardized to track success and accountability. Parents need to be educated on what to ask for from their team. There is some concern about what the Regions will say about the system of care approach.

Some expressed the idea that services for youth needs to be different than services for adults. Mr. Martone acknowledged that the children's system has unique needs, but cautioned the workgroup about creating a system in a vacuum or silo will cause service recipients and the system as a whole suffer.

Mr. Martone presented an Iowa **DRAFT** system of Care Definition:

A spectrum of effective, community-based services and supports for children and youth with or at-risk for **mental health** or other **challenges** and their families, that is organized into a coordinated network, builds meaningful partnerships with families and

youth, and address their cultural and linguistic needs in order to help them function better at home, school and in the community throughout life.

Discussion ensued about the definition. The workgroup suggested that additional considerations to the definition be made:

- Do we use mental health or behavioral health in lieu of mental health?
- Behavioral and emotional health may capture it better/best.
- Adult services have an emphasis on recovery.
- Physical health and **mental health** are interrelated.
- Do challenges include disabilities?
- Other challenges to consider: economic. Do not exclude any challenges for any one child.
- Substitute challenges with disabilities.

Other factors to consider in the System of Care Definition:

- The Health Home Concept: who is/out of Health Home? There needs to be consistency on who gets involved from the Health Home to be part of the System of Care. A Health Home is for individuals with chronic conditions and multiple providers. A Medical Home is for everyone.
- Focus on a narrower set of services for youth.
- Start with prevention services for youth, not just adults. Move to a more integrated system that crosses child welfare and mental health. Begin to look at funding streams, transition and discharge plans for OOS youth and rationalize funding streams to bring the OOS youth back to lowa.

It was noted that the word system was not in the working definition as noted above.

Other comments to consider in the working definition of System of Care:

- Always build child and family in the center.
- Build in funding and services that are flexible to the youth and family. Funding is not flexible enough now.
- Main coordinator is not staff from the child welfare or juvenile justice system.
- Broaden the definition to include youth with disabilities.
- Identify social determinants of health.
- Add other governmental agencies within the definition: Iowa Workforce
  Development, Iowa Department of Public Health, Iowa Department of Education,
  etc.

TAC will review these considerations and present a revised working definition of System of Care for the next meeting. The definition will contain outcomes to refer to over time. The outcomes will focus on the youth and family in the center and the Olmstead Plan, which are applicable regardless of age.

The workgroup discussed outcomes next. The Core Service Domains to consider:

- Family Support
- Community Living Supports: Care Coordination
- Employment & Recovery Supports
- Health & Primary Care
- Crisis Prevention & Intervention
- Acute Treatment
- Mental Health Treatment

The workgroup then identified what services will be needed under each Core Service Domain.

#### Family Support

- Respite
- Child Care
- Transportation
- Culturally Competent
- Natural Supports & Settings
- Resource Flexibility
- · Single Point of Access: no wrong door
- Family Support Groups (flexible)
- Family Education
- Community Collaboration/Access
- Family Team Meetings
- Family Peer Support
- Family Navigator

#### Community Living Supports: Care Coordination

- In Home Family Therapy
- Transportation
- Social Skills/Recreation
- · Child Care
- Respite
- Wellness Activities
- Basic Needs Assistance: food, clothing, shelter
- Money & Credit Management
- Case Management: use concept of Child Health Specialty clinics and Title V funding
- Specialized After School Programs
- Cross Disability Supports
- · After Hours access
- · Education: home, other
- Extra-Curricular Supports
- Advocacy

## **Employment & Recovery Supports**

TAC will work on title of this core service and consider using Vocational in the title.

- Supported Education
- Supported Employment
- Peer Support
- Job Shadowing
- Assessment & Evaluation
- Job Readiness
- Service Learning
- School Supports: early childhood settings for youth ages 0-5
- WRAP/Recovery Planning & STEPPS Program
- Transportation
- Assistive Technology

#### Crisis System – with family support

- 24-Hour Call Service/Hotline
- Crisis Respite
- Early Identification of Triggers: decision tree on who to call and when
- · Schools: include guidance counselors and school nurses
- Intensive In-Home Services

"Help me Grow" for the younger youth ages 0-5 is currently being developed in lowa as an early intervention service.

There was a note from the workgroup that there is a push and pull with families who have different definitions of crises other than DHS' or other professionals'. There are also other individuals who are in crisis that are in denial and cannot share/acknowledge the truth about what is occurring.

#### Mental Health Treatment

- Residential Services: PMIC, Foster Group Care, Substance Abuse Residential Partial Hospitalization or Day Treatment
- Individual Therapy
- Group Therapy
- Medication Management

A short discussion then followed on what is needed to begin to bring out of state children to services back in state.

The group listed the following beginning components as necessary to be in place in order to begin to bring children back in state:

- 1. Some crisis response and diversion services must be available. This could include crisis residential/respite and mobile response.
- 2. Home-based Services. These could be a range of in-home or intensive in-home services. The group loosely defined home as his/her actual home and foster care.

- 3. The creation of multidisciplinary teams regionally that can conduct a thorough assessment of a child/family needs is essential. This team should have some authority in then authorizing the action for these additional, intensive, wraparound services.
- 4. Discussed next was the development of a mechanism to authorize flexible funding to provide the necessary array of services that could take the form of pooled funds under some authority to pay for services. Several commented that the existing reimbursement system's rigidity is a major barrier.

Before moving onto public comment, Director Palmer commented that a flexible array of services must be incorporated into Medicaid waivers or state plan services to the extent possible.

#### **NEXT STEPS**

Information requested for the next meeting: none.

#### Meeting 4 Agenda:

- In reference to OSS kids, what do we need to build up right away? We need to
  develop a system that helps to keep a kid from leaving the state for needed
  services.
- TAC will bring a definition of System of Care.
- TAC will identify Core Services for Employment and Recovery Supports, Health & Primary Care, and Acute Treatment.
- TAC will take the Core Service Domains and indentify Core Services for Children, Core Services for Parents/Guardians and Outcome Measures for Domain.

#### **MEETING SUMMARY**

- Group began to outline the framework to bringing youth in an OSS placement back to lowa.
- Core Service Domains: identified services needed under Family Support,
   Community Living Supports, Employment & Recovery Supports, Crisis System,
   and Mental Health Treatment.

#### **PUBLIC COMMENT**

Comment: I found the last conversation very interesting. Iowa actually

had all the levels of care that were discussed. I used to work on a unit where we served kids with Conduct Disorder. Initially there was a lot of controversy with the program but many of the kids were discharged successfully. There were a few kids whose needs could not be met with this program.

We used to take care of kids in Iowa.

Comment: I work with the Community of Circle of Care (CCC). We have

done the preparation work with the communities and the communities were ready for the kids. We asked the kids and

their families what they needed to be successful. Do not forget about what we have now, and then offer what is available to the family. We have done it. One youth had 30 different placements and was highly aggressive. This youth is living with family working in the community and attending college.

Response: This revolves around good relationships with the system.

The cost may be more or it may be less but there is a shift in

thinking that needs to happen.

Comment: I want to advocate for what CCC shared. There is a Family

Team Meeting that occurs before a child goes out of state. I did not know what I needed at that time. There is not enough authority at the Family Team Meeting to make any decisions. I need to have the opportunity to talk about philosophical questions that I need answered. Too often Professionals dismiss the information provided by parents. Assessment

tools need to be comprehensive.

Response: I appreciate your perspective. It is our charge to make what

you need visible and available to you. Our assessment is critical. We are learning more information about medical

conditions that contribute to overall well-being.

Next meeting is on September 27, 2011 at the United Way Building in Des Moines, lowa.

For more information:

Handouts and meeting information for each workgroup will be made available at: http://www.dhs.state.ia.us/Partners/MHDSRedesign.html

Website information will be updated regularly and meeting agendas, minutes, and handouts for the six redesign workgroups will be posted there.